After the Crisis Initiative: Healing from Trauma after Disasters

Resource Paper:

From Relief to Recovery: Peer Support by Consumers Relieves the Traumas of Disasters and Recovery from Mental Illness

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Recently, as I was concluding a very lengthy teleconference on a Friday evening with peers from Meaningful Minds of Louisiana, I asked the group why we were so committed. Quietly, we heard the gentle voice of Nelda from Alexandria, "because we love each other." – Daniel Fisher

Introduction

This paper is about the love and solidarity, which grow from the suffering that people with mental illness understand first hand. We, who have been through the traumas of the disasters of our lives, immediately understand and feel impelled to respond to the victims of shared disasters. At times of disaster, peer support has served as a vital complement to professional services. Following the bombing of the Murrah Building in Oklahoma City and the destruction of the twin towers in New York City on 9/11, mental health consumers provided valuable peer support services to traumatized individuals. Much like in New York, peers are also being mobilized to assist in relief efforts in Louisiana following hurricanes Katrina and Rita.

This paper describes how the peer-based, recovery approach to assisting those with mental illness following disaster is consistent with crisis counseling following disasters. This means that peer support not only provides relief from trauma, but in so doing assists in peoples' recovery from mental illness. Mental health consumers' experiences with recovery from a variety of trauma have equipped us well to assisting people at times of disaster. Indeed, the shift in role from passive victim of a disaster to active agent providing assistance plays a valuable role in relief from trauma, as well as recovery from mental illness. The state of Louisiana following Hurricanes Katrina and Rita serves as a case example of the challenges and advantages of providing peer support services. From the Louisiana experience and others discussed in this paper, it is clearly important to prepare for disasters proactively by developing a network of peer supporters across each state.

History of Consumer Involvement Following Disasters

Peer support following the Oklahoma City, Oklahoma Bombing and Tornadoes

Oklahoma City experienced the bombing of the Alfred P. Murrah Federal Building in 1995. This was the first time that the heartland of the United States experienced an internal attack of terror. The effects of the bombing resulted in a scene similar to terrorist attacks and acts of war in other countries. Not only did we experience the loss of a major hub of work, 168 lives, and over 1,000 injured, we also experienced the destruction of many businesses, homeless shelters and condos that were within the six block radius of the bomb site. The shock of this event would have an impact on mental health services for years to come. — Kay Rote, Director of the Oklahoma Mental Health Consumer Council

Personal involvement and pressure from national consumer leaders allowed the Oklahoma Mental Health Consumer Council (OMHCC) to be included in the resulting Federal Emergency Management Agency (FEMA) operation known as Project Heartland. A mere \$70,000 was allocated to OMHCC for the express purpose "to aid individuals in returning to pre-crisis functioning levels, to alleviate acute mental distress related to the bombing, and to assist in the re-establishment of social bonds and support networks fractures by the bombing."

Immediately, a training course for peer counselor/support was developed to train and certify the first groups of consumer leaders to complete the following:

- Peer level crisis counseling
- Set up community support groups
- Provide extensive community outreach
- Provide referrals to more long-term care
- Home visits
- Transportation

On May 9th, 1999, Project Heartland was re-activated after the world's largest tornado disaster ripped apart 16 counties in Oklahoma, totally devastating everyone and everything in its path. OMHCC requested to be a part of the newest FEMA project, and was granted another \$70,000 for consumer peer support and outreach.

This type of program is powerful and economically valuable in providing assistance in necessary referrals and preventing unnecessary hospitalizations at state psychiatric hospitals and emergency rooms. Consumer peer support stationed at hospitals proved to be invaluable in their ability to reduce anxiety, expediting the initial intake and discharge process as well as referral to other services and support groups when hospitalization was not necessary. Consumer peer support was commended for their ability to "triage" those most directly affected by the disaster, especially when pre-existing mental health issues were present.

What we learned from this experience:

- Initial assistance is provided to the local citizenry after the disaster with strongest need for outreach.
- Remain in contact with initial citizenry participants, first responders, rescue teams, and reconstruction workers.
- Watch our children carefully. The continuous onslaught of media coverage as well as the repetitive scenes and inane heartbreaking interviews will have a profound effect on younger children.
- Elderly populations that have childhood trauma will probably experience severe flash back and Posttraumatic Stress Disorder (PTSD). This is true as well for those in the military that have experienced combat.

- One-year anniversary of both events brought the largest initiation of service to first responders and rescue workers even though continuous debriefings were held.
- Two years from each event brought participants who were long-term care providers, mental health professionals, and reconstruction teams, as well as persons who had never before experienced issues such as PTSD, Depression, and Bi-polar symptoms.
- As much as five years from event there was an increase in the number of persons who were experiencing trauma-induced behaviors without any understanding of mental health issues. These referrals came particularly from family members and business partners seeking help for another person. We saw many who were in extreme denial, despite behaviors reaching a point of needing crisis intervention. Family members could pinpoint the initiation of "odd" behavior that gradually worsened due to lack of understanding and early diagnosis.

Project Liberty following the September 11th Terrorist Attacks

The following is an abstract of an evaluation of the Project Liberty Peer Initiative (PLPI), prepared by Hardiman, Carpenter, Jaffee, & Gourdine (2005).

The Project Liberty Peer Initiative (PLPI) program represents an innovative and successful effort to provide a range of mental health supports to individuals with psychiatric disabilities, a population thought to be particularly vulnerable to the impacts of trauma and the potential recurrence of post-traumatic stress-related symptoms.

Those individuals who participated in PLPI services, either through provision or receipt of services, collectively shared a fascinating and compelling story of compassion, dedication, mutual aid, connection, and community following the devastating effects of a horrible disaster with far-reaching potential for traumatic impact. Individuals with psychiatric disabilities (mental illnesses) living in New York City were able to organize together, apply for federal relief monies, and successfully reach out to more than 10,000 people throughout the New York metropolitan area. Recipient interviewees described PLPI services as absolutely critical in the restoration of meaningful post-disaster lives. Our data, taken in combination with the quantitative utilization data captured by Project Liberty, indicate that the program was incredibly successful in meeting its goals and that it dramatically impacted the lives of thousands of individuals.

Recipients of PLPI services gained access to valuable supports, including individual counseling, group sessions, and after-hours telephone support. Perhaps more importantly, they were exposed to other individuals like themselves, who had experienced psychiatric disability and were struggling with how to cope with post-September 11th life.

There were a number of activities of peer support found to be of value to both the participants and the peer workers such as:

- Shared Identification. The significance of identifying with a peer who is in a service provision role was a recurrent theme for almost all PLPI recipients. One PLPI staff member described this identification process, "peer support, you understand...people have gone through the same things. It's like, difficult for me to talk to somebody about crack who had never smoked it... So I like to be around people who know this...and I can talk to them about it and they can identify with me and I can identify with them." Another participant described the PLPI group experience as "very supportive to me because I was able to identify with a lot of things concerning my mental history."
- The Importance of Listening. The majority of participants placed tremendous emphasis on the role of listening within the peer support services offered by the PLPI program. Listening was defined by one recipient as the ability "...just to hear other people's problems, what they had to talk about...and to compare those to what I had gone through in the past." Listening was perceived as a rare quality among service providers, and the afore-mentioned credibility of peer providers combined with an ability to actively listen to recipients proved an effective combination for many group members. As described by a recipient, "I felt that I could open up to this person and tell him my true feelings about what I'm doing with my life. And he listened. I didn't have that in my life before...someone to just listen."
- Promoting Choice and New Alternatives. Many participants indicated that the experience of receiving formalized peer support services through the PLPI program allowed them access to new resources, increased choices in their lives, and new alternative ways to live in the community. PLPI groups were described by recipients as "opening new doors" and "shining a light on new things." Through participating in the exchange of peer support, being treated as equals, and perhaps most importantly helping other peers, individuals were able to construct new possibilities for their lives. One recipient indicated that "The peer movement will motivate you. You will get support, you will get resources, something that you might not get in other areas in other agencies."
- Credibility and Authenticity. Many of the other elements of peer support fed into the credibility of PLPI peer providers. For instance, shared identification made peer provider's encouraging narratives more feasible to consumers. One recipient said, "When you're dealing with someone and they identify with what you've gone through...you feel like this person's not lying to you...And his diagnosis, he was schizophrenic, and he has depression...he didn't let that stop him from leading a normal life." Perceived credibility and authenticity also went hand in hand with role modeling for most participants. If a peer provider was perceived as credible, 'real', and knowledgeable, there was a greater likelihood that group members would also view him or her as an inspirational role model.
- Collective Sharing. The mutual reciprocity of the sharing process had a powerful impact on many PLPI group members. Several indicated that they had never

attended a group in which a true mutual exchange of support occurred. One person said, "the same way we came to them, with...things we felt that were bothering us, they would confide in us. That's where I got my information from. They would confide in us, in the group and in me at the same time." Another said, "...I mean it's a two way thing...it's no good unless you're giving it away, because it's coming back. It's coming back, believe it or not."

This story should be heard by administrators and planners of disaster relief services, and should be considered in planning for future disaster relief efforts. The core principles of peer support that provided the framework for the PLPI program offer a natural, respectful, flexible, and community-based way to provide mental health support services based on shared life experience. Rather than being devalued, stigmatized, or ignored, peer-delivered mental health support services should be incorporated into all stages of planning and implementation for relief efforts following a large-scale public disaster.

The Director of the Howie T. Harp Peer Advocacy Center, LaVerne Miller, shared the following:

Peers are often overlooked as an invaluable resource in assisting state, local and federal governments in creating disaster plans that meet the often unique needs of mental health consumers. Similarly, they have been overlooked as potential first and second responders capable of providing crisis counseling, support and public education to other consumers and others impacted by a disaster. This frequently results in the development of disaster related services that have little or no impact in relieving the suffering of mental health consumers.

The Howie T. Harp Peer Advocacy Center, in collaboration with NYAPRS, the Mental Health Empowerment Project, and several other consumer leaders, developed the Project Liberty Peer Support Initiative in response to our concern that many consumers were re-traumatized by the 9/11 tragedy and that traditional mental health care providers were unable or unwilling to meet the increased needs of this community. The services provided were individual crisis counseling, group counseling, and public education. The initiative also created a warm line providing support services to consumers from 5:00 PM to 12:00 AM and on weekends.

Five of the initial 30 outreach workers and two senior staff members employed by the Project Liberty Peer Support Initiative were mental health consumers with a history of incarceration in jail and or prison. All five of the outreach workers and one of the senior staff members were employed for the duration of the project (February 2002 to August 2003) and all transitioned to competitive employment positions following the end of their tenure with the Project. Peers worked in wide range of settings ranging from the subways and streets, traditional metal health programs such as clinics and day treatment programs, to emergency rooms, and in city hospitals.

Interviews with these staff regarding their experiences and the experiences of mental health consumers with histories of incarceration who received one or more of the services offered by the initiative strongly suggests that most were re-traumatized by the disaster and that peer-provided services assisted them in connecting with the larger consumer community, introduced them to concepts of self-help and recovery and most importantly helped them identify and gain access to traditional and peer-driven mental health services.

One of the most significant lessons learned was that peers are capable of providing crisis services without "decompensating" or becoming ill due to the stressful nature of the work. Like all workers, staff benefited from training designed to mitigate the stressful nature of the work and ongoing support but all agreed that employment and the "act" of helping assisted their own personal recovery. One senior staff member observed that "we spend virtually all of our lives coping with one crisis after another, who is better prepared to help than those who are experiencing the darkness and despair that we see than those of us who bear witness to triumphs over darkness every day of our lives."

The Empowerment Model of Recovery from Mental Illness is a Useful Basis for Recovery from Trauma

The recent emphasis on recovery through empowerment and peer support among consumer groups gives consumers a unique capacity to assist each other and those not yet labeled at times of disaster. The principles of recovery from mental illness are consistent with recovery from trauma. In fact, the theme for recovery from trauma at times of disasters, that people are having normal reactions to abnormal situations, fits with the philosophy of trauma-informed peer support emerging from the lived experiences of consumers. The recovery approach in mental health has emphasized that consumers need the relationships and skills to enable them to (re)gain control of their lives. The Empowerment Model of Recovery (Ahern & Fisher, 2001; Fisher, 2006), developed at the National Empowerment Center (NEC), fits nicely with the trauma model of recovery, as they are both rooted in people's lived experiences. Peer supporters often understand this strengths-based approach better than professionals whose training has emphasized the model of the expert removing pathological symptoms. Perhaps the greatest contribution of peers in assisting persons in disasters, personal and community-wide, is our special way of being, born from painful experiences. Having gone through our own suffering, we as peers can offer a way of being in the world which can promote the healing within, essential to recovery from trauma. We are not trying to control the other. We just try to be with them deeply in such a manner that they can regain control of their lives. This may be the essence of mutual support. At a deep level we share the conviction that we are fellow travelers. That the other person's suffering is our suffering. In Louisiana, we called this the solidarity through suffering. We also bring an urgent emphasis on the present moment, which is where growth begins (Stern, 2004). There are so many distractions from the present moment in times of crisis, yet we need to be able to return to it.

Many of the principles of peer support (Holter, Mowbray, Bellamy, MacFarlane, & Dukarski, 2004; Salzer, 2002; Solomon, 2004; Solomon & Draine, 2001), such as the peer principle, the helper principle, empowerment, and advocacy apply equally at times of community crisis. Peer principle: affiliation with someone with a similar form of life experience and having an equal relationship; Helper principle: being helpful to another person helps one's own recovery; Empowerment: gaining confidence in one's own capacity to make decisions and have control over one's life; Advocacy: positive risk taking, support, sense of community (Campbell, 2004). In addition, Mead has emphasized the need to maintain a mutual relationship, despite one person being designated the helper. She thinks a great deal of this shift is achieved through a new use of language in describing the problems and through uses or narratives in the person's own voice instead of professionally authored versions (Mead, 2005).

From Relief to Recovery after Katrina and Rita in Louisiana

Louisiana is a living example of the promise and challenges of peer support following disaster. In many ways the involvement of national and local consumer leaders in Louisiana helps us understand the variety of opportunities and challenges of peer support at times of disaster. Peer support has become an instinctive reaction to suffering among those of us who have suffered severe emotional distress. We felt compelled not only to act but also to get involved in a personal manner with the consumers in Louisiana. This is likely because there is a strong bond formed among consumers dubbed by one peer, the "solidarity of suffering." Therefore, there was a positive response to NEC's request to assist the consumers in Louisiana from consumers across the country. Through teleconferences, NEC helped establish in 2 weeks, a national consumer disaster advisory group which named itself Consumers Organizing for Recovery after Katrina or CORK. With the addition of consumers from Louisiana, this group became LaCORK. After the devastation of Katrina and Rita, mental health consumers across the country, like everyone else, wanted to assist the people affected by the hurricanes. Joseph Rogers and members of the Self Help Clearinghouse assisted people in Texas. Patrick Hendry and another consumer drove an RV from southwest Florida to assist people in Mississippi.

The following is a very moving account by LaCORK member David Romprey, an advocate from Oregon who accompanied me on both my trips to Louisiana. We formed a very good team, with his doing much of the connecting and my doing more of the organizing.

People who go through natural or other disasters have different reactions to the stress and trauma of such events. Persons who are diagnosed with mental illness also vary in how they respond to emergency or life-threatening calamity. It adds to stigma and stereotypes to assume that public mental health consumers will react less strongly, or more fearfully, during regional chaos and tragedy.

As our nation turned to hear and feel the rage and bragging rights of hurricane personalities Katrina and Rita, I was left in another kind of mind-bending wake. What

stunned me more than the two Super-Sized Storm Sisters was what a broken life (by virtue of years of isolating and dignity-stripping mental health treatment) could do for others during such an hour. I was privileged to advise a team of peer trainers in Baton Rouge, Louisiana on their goal of outreach to other mental health consumers in their surrounding area within two weeks of the main storms hitting the Gulf Coast.

In Louisiana, while government officials and their staffs from the parish to federal level were scurrying between press releases and performing acts of heroism and outright common sense to meet the needs of the people, the state's public mental health recipients were not forgotten. Louisiana's Department of Mental Health and its director Dr. Cheryl Bower- Stephens were working fast and effectively to identify any disaster-related needs of psychiatric patients, predicting and preparing for "relapses", and setting up mobile response teams to ensure that medications and diagnostic services reached all of their charges no matter what shelter or where they may have relocated to. What wasn't known to the Department was that a self-styled yet deceitfully deep band of "mental patients" was busy organizing their own recovery – and redemption.

Meaningful Minds of Louisiana blew my mind – turned over the very streets that were meant to deliver their help by instead stirring and unfurling a hurricane of hope. As a people stigmatized to be in need of perpetual help and trained guidance, they instead transformed themselves. Yet another Governor's burden became instead a powerful partner in the solutions of Louisiana's post-disaster planning.

By refusing to be further victimized and marginalized during the storms that captured our worst fears as a nation, Meaningful Minds trained and encouraged their peers and communities. Refusing to be considered helpless, they instead hoped themselves and others to new life. The lesson of Baton Rouge was an example and show of force in my life to believe the best of all people, and not fear their fears for them. I only fear, to be honest, that what Meaningful Minds did for each other will not somehow serve as way of teaching hope to us all.

Another member of CORK, Beth Filson, who heads the Georgia Peer Specialist Program, gave the following description of her training and organizing in New Orleans following Katrina:

In the past decade, due to the increasing frequency of disasters, peer support has had to encompass more than the commonality of our lived experience with mental illness. We who are consumers/survivors/ex-patients have shared with our non-peer neighbors, colleagues, friends, and still others the event of communal catastrophe – the collapse of our known external systems of supports. Tragically, disaster has now become an equalizing force in our society. In community, every person's acts have the potential to be heroic. Alone, assumptions about people with mental illness place us at terrible risk for ongoing trauma and further alienation from others. It is a matter of survival to come to some reckoning about what it is we bring as human being to these scenes of so much despair – allowing us to actively connect and keep on connecting to each other; to seek out each other, to keep on demanding from each other that for every blow, there must be

another peer led response. Peer Support will keep on evolving as we all become more deliberate about our presence in each others' lives – from crisis and disaster preparation and planning, to surviving its impact, to incorporating the new worldview catastrophe will always frame. We are already refuting the notion that there can ever be a return to a "pre-crisis levels of functioning." – for anyone, consumer and non-consumer alike. We are always, irrevocably changed. The litmus test of our survival is what we think about those changes, and how we incorporate those changes in our peer support communities and in the larger context of our world. This is the genesis of making meaning out of our lives. In the dawn of incorporating trauma-informed mental health systems, we understand the absolute necessity of hearing all our stories within the scope of our whole lives.

Despite the fact that I spent a short period of time with a group of train-the-trainers in Jefferson Parish, three things were reaffirmed for me about what peer support in my own life has meant: That bearing witness to another's grief is a profound act, that people live in multiple contexts and we never really know them all, and, finally, that there is an insatiable need in all of us to be heard.

Disaster lays bare the whole continuum of human experience – not just the experience of mental illness –along which we are able to take part with each other in the entire, complex, mysterious, sometimes terrible, condition of being human. Disaster leaves us with no alternative but to survive, or assist others in their survival. This breadth of cultural, physical, personal, spiritual, and experiential diversity has become a measure of our communities' resilience. In the consumer/survivor/ex-patient community, this is our shared wisdom. We've known this. Maybe the only change is that today I feel its greater urgency.

Prior to conducting a train-the-trainer on peer support for a group of c/s/x in Jefferson Parish, my first contact with the tragedy in Louisiana took place in my home state – as a volunteer at different Crisis Relief Centers in Georgia. One of these centers was Dobbins Air Force Base. Volunteers from various state agencies hoisted people on stretchers out of airplanes, or assisted others with the support of medics, and other personnel. For the most part, these were the most vulnerable – mothers with newborns, nursing home patients, hospital patients, the sick, the infirm; the ones who could not have evacuated on their own and had been impacted by the ordeal of surviving the floods. A colleague of mine described this scene: A woman arrived in four point restraints. The most prominent indication of her condition was a large tag on her chest that read "SCHIZOPHRENIA." Her boyfriend hovered anxiously around her pleading for someone to take her out of the cuffs. There was no indication of psychosis. She was conspicuously calm despite her circumstances. However, the fact of a history of a mental illness, and her ongoing medication regimen, had been enough to warrant disregard for further assessment of her state of mind. She had been indiscriminately restrained for transport. Assumptions about how people with mental illness will respond to catastrophe had robbed her of her self-efficacy. My colleague stayed with the couple until she was able to wrangle a physician to the gurney where, after seeing her condition and knowing

the circumstances from which she had been airlifted, he destroyed the orders for her transport to a state facility stating that there was no indication for commitment.

In Jefferson Parish, two participants in the training, also consumer/survivor/expatients recounted their experience with Katrina: Harry did not sleep for five days. His partner, Sue (not their real names) confirms this with a huge, somber nod. Instead, he sat on the carport at night with a gun in his lap. He had no choice. He makes me understand this. He had NO choice. There's looting – fires on other streets. Snipers are firing at helicopters overhead. Sue explains the terror she felt. She uses her eyes and mouth and posture to explain this because it seems that the word "terror" itself is not enough to convey the largeness of her experience. There is a kind of panic in Sue's body that mere memory provokes and makes palpable around her. She describes how Harry crawled on all fours down to the storm drain in the midst of the hurricane to clear away rubbish and timber that threatened to flood their street. They go back and forth like that, telling their story. Harry watches Sue talk. Sue wants me to understand what Harry did. I learn how Harry forayed out during the day for Meals Ready to Eat (MRE), water, whatever he could find. Sue confirms that he kept them alive. Somehow he'd gotten his hands on an all-terrain vehicle. He kept it gassed by siphoning fuel from abandoned cars. He'd leave his name and address under the windshield wipers, he said. He traded information with other stranded neighbors along his route. He found out what they had, what he could barter, what they needed so he could keep his eyes open for them...

Since my trip, I have come to believe that the indiscriminate determination of people's needs based on the premises of a mental illness must be the luxury of those who do not need to rely on each other for survival.

It will take a while, I believe, to shape into a meaningful body of knowledge all our experiences – to be able to talk dispassionately about how we respond to disaster, and how to strengthen our own communities of intentional healing and support. We have turned our focus more and more to this task – to create meaning out of events like 9/11, the Oklahoma City bombing, and now, Hurricanes Katrina and Rita. In the end, I know that I had nothing to teach my peers in that dusty training room in Jefferson Parish. Maybe the only reason I was there was to be present. While present. I saw Martha across the room quietly crying. I stammered, "What's wrong? What is it?" as if there needed to be more to all that devastation. She said quietly, and with finality, "All my dreams are dead." I knew in the ensuing silence that our work began then... This work will take a lot of us.

Daniel Fisher recounted the following:

In late September, David Romprey and I spent two days in Louisiana strengthening the local consumer-run organization, Meaningful Minds of Louisiana (MML). We carried out community organizing to assess the supports present and supports needed. We also established a working relationship with the Louisiana Office of Mental Health. The consumers' urgently requested training in peer support and crisis counseling. They also wanted a written curriculum on these topics. During the next three weeks, LaCORK

assembled such a curriculum (CORK Team, 2005). The major topics in the curriculum are recovery from mental illness and its relationship to crisis support, peer support, cultural competency, warmlines, and psychological first aid.

From October 17 to 21, 2005, I and four other national consumer trainers provided training in peer support to 46 Louisiana consumers. NEC identified experienced trainers: David Romprey from Oregon, Beth Filson from Georgia, Ike Powell from Georgia, and Laverne Miller from New York. David has ten years of experience in organizing consumer groups, Beth and Ike have developed and carried out the peer specialist trainings in Georgia and many other states. Laverne had experience running Project Liberty Peer Initiative following 9/11.

It is hard to find words for this life-changing experience. Trainers and trainees alike have been profoundly moved by the experience (as evidenced by their testimony in this paper). The people of Louisiana captured our hearts. We found solidarity in our suffering. They all had a story to tell and we listened. The training was itself the embodiment of the spirit of peer support. In that spirit, we the trainers were helped as well. As a peer from Michigan had recently shared, "the trainings transformed the poison of mental illness into a medicine we could share with our peers." Several Louisiana peers have explained that the tight bonds formed through our work and social gatherings over gumbo are based on love. I would agree. Peer support was as much a factor in the process of our work as in its outcome.

MML and the Louisiana State Office of Mental Health, Office of Consumer Affairs played an enormous role in coordinating the trainings. They selected the participants and secured the sites and housing for trainees and trainers. Of particular note were the efforts of Denver Noble. He went to his church and appeared on TV appealing for housing. Through these efforts, he secured housing for 12 trainees and a trainer in the Lafayette area. Sylvia Pearson, of Extra Mile, was able to find hotel space in New Orleans area for 2 trainers and a trainee. These were all remarkable feats considering the devastation around them and the stress they were all going through.

There were a number of other benefits, which resulted from our presence there. The trainings gave the trainees an opportunity to share their feelings about the disasters. At the New Orleans site, one trainee said he experienced flash backs related to his traumas in Vietnam. Another trainee said the disasters reminded her of the holocaust which her parents had survived. Another trainee, a taxi driver, took two of the trainers on an emotional trip around the devastated parts of New Orleans. The trainees also wanted to know how they would put their training to use. In addition to applying the lessons learned in assisting their peers informally, the leaders of MML wanted to ensure that peer support was a part of the FEMA grant the state needs to submit. The trainers assisted MML and the OMH Office of Consumer Relations in outlining ways that mental health consumers could participate in setting up several warmlines and peer support centers. The trainers also facilitated a meeting between the officers of MML and the Assistant Secretary of State of Department of Health and Housing (DHH) for Louisiana, Dr. Cheryll Bower-Stephens. Dr. Bower-Stephens understood the importance of an

independent consumer voice and peer support. Debra LaVergne of Lake Charles, executive director of MML, showed great courage. Despite her house having lost its roof and being covered in mold, she organized a van of 8 trainees to come up from the Lake Charles area for the training. Daily Dupré, a long-time consumer leader and member of MML and Carole Glover, President of the board of MML, also deserve special recognition. Through their advocacy with OMH they were able to ensure that the trainings took place. Our first contact in Louisiana, Margaret Mitchell, Director of the Office of Consumer Relations, has been a consistent supporter, recruiter of trainees, and organizer.

In early 2006, Linda Donovan, a doctoral student from Arkansas spent several days interviewing the peers in Louisiana who received the training in October. She shared the following moving feedback from the impact of the trainings:

- I'm saying more. I used to not talk as much. [The thing that made the difference to me was] having a psychiatrist, especially a recovering one, telling you this is something you can do and will make a difference to you and to other people. All [of the group was] excited about [hearing that] there was something they could do that they could benefit other people based on their experiences. Mentally ill people were capable of having responsible jobs [-t]hat they had something they could offer.
- The thing that made the difference to me was the representation of the level of the humanity of the people doing the training for us.... I could notice a difference in me relating to them I'd never related to anyone at that level. It was a group but felt like one-on-one. It was really something else!
- The thing that made the difference [about recovery] to me was to see a person who was diagnosed and a person not diagnosed on the same page about recovery.... [T]hat commonality was just unreal it really was.
- What the training [meant] to me was it made me aware that we could make a difference to other consumers' lives with the proper training.
- The biggest benefit I got from the training was to help set up the training, being involved in the preparation was a high for me[,] the anticipation of what would be taught and how well it would be received. Looking around the room and viewing the faces soaking up the information like a sponge so this information can be used to aid another one of our peers when a circumstance or situation would arise.
- For me to know recovery is possible was to just look around the room of the training because it was obvious the information we were getting was changing lives right in front of me. Excitement grew, statements of self esteem [were] made, and action was being taken during the training through participation in the training. Each day of the training everyone was more and more energized to make positive changes in their lives to provide for a deeper recovery.
- [The thing that made a difference to me] was hearing about Peer Specialists and how one person can make such a difference in other people's lives like Dr. Dan Fisher. I have always been told "you don't get recovered from mental illness." Well, I have found out that that's a lie and I can recover and live a full life without mental illness.

- After training I felt I was on the right track with the person-to-person approach and in a word empowered.
- One of the things that I have noticed about some of my "Peers" is they have gone to work! Not just volunteer work... real work! Amazing. I believe they have the moral support of people on the net to help ... there are more resources, too!

Meaningful Minds participated in several trainings nationally: they presented their experiences, as members of a panel, to 900 participants of the Alternatives Conference in October 2006 and in a webcast, sponsored by the Substance Abuse and Mental Health Services Administration [SAMHSA] on peer support and disaster relief on December 15, 2005 (SAMHSA, 2005).

In a deep sense, I have learned important lessons about what it means to be a peer helping others. First of all, I realize how different it is to help on a peer-to-peer basis. We lead with our heart not our head. We enter into relationships first and foremost then we see how we can assist the others. This is the opposite of professionals who often enter at the thinking level with theories about what they will see. Then they try to draw out the person's feelings but by then the person is further defended. The formality of the traditional system combined with the power differential between professionals and those in need of assistance additionally make opening up more difficult. A nurse shared this observation with me in Japan. She said, "I envy you all who have been struggling with mental illness. You know first-hand the feelings of the experience and that enables you to share a bond we who have not been there can never understand." Peers can take the lead in times of crisis, and in so doing build the bridges of trust between people suffering and professionals who want to help them. We are willing and capable of bridging these worlds as well as providing support. We are a resource the system cannot afford to overlook.

Empirical Support for Peer Support Services

A theoretical foundation for peer support services suggests that these services can be an important tool in the recovery process. "[S]ocial learning theory (Bandura, 1977) suggests that behavior change resulting from interactions with peers may be more likely because peers are perceived to be more credible role models and enhance self-efficacy" (Salzer, 2004, p. 5). Thus, an individual experiencing psychological trauma as the result of a disaster may be more likely to feel hope because of their interaction with a mental health provider who can relate to their trauma based on personal experience and provide a positive role model, both of which can contribute to the return to pre-disaster level of functioning.

Social comparison theory (Festinger, 1954), Salzer (2004, p. 4) states, individuals "seek out others with similar [experiences] in order to help them maintain a sense of normalcy and understanding of the world." Peer support, as described by Mead, Hilton, & Curtis (2001, p. 135), "is about understanding another's situation emphatically through the shared experience of emotional and psychological pain." The conclusion can be made that a significant benefit of peer support services is the common understanding between provider and recipient.

Peer support services are "an important approach to expanding the continuum of services available to persons with mental illness" (Salzer, 2004), and can be an important community outreach tool. In March 2002, following the disaster in New York City on 9/11, Project Liberty Peer Initiative [PLPI], "a peer-delivered program designed to provide mental health supports" (Hardiman, Carpenter, Jaffree, & Gourdine, 2005, p. 5) began operating in 70 service sites throughout the city. Of these sites, two Moynihan, Levine, & Rodriguez (2005) found that many clients who received services from PLPI sought support for a mental health condition that was present prior to 9/11. Disasters - in this instance, the events of 9/11 - can provide a socially acceptable opportunity to seek support for those who were previously reluctant to engage the mental health service sector (Allen, 2005; Moynihan, Levine, & Rodriguez, 2005).

In an evaluation study of PLPI, conducted by Hardiman et al. (2005), recipients of these services stated that the peer support was the most important service because of "shared identification, collective sharing, credibility and authenticity, importance of listening, and promoting choice and new alternatives" (Hardiman et al., 2005). The peer support model, "founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful" (Mead, et al. 2001, p. 135), can support the process of recovery by supporting choice which can lead to consumer empowerment. "Empowerment is associated with greater self-efficacy, confidence, and hopefulness" (Zimmerman, 1990).

Although the empirically based research on the benefits of peer support and consumer services is limited – many studies have been limited to descriptive studies - the few methodologically sound studies have shown positive outcomes (Felton et al, 1995; Klein, Cnaan, & Whitecraft, 1998; for a review of studies, see Solomon & Draine, 2001), mirroring the personal experiences of these authors.

Conclusion

Each state should develop a disaster plan that includes peer support services. These peer support services are best coordinated by a state-wide consumer organization. The experiences in Louisiana and Oklahoma have illustrated the importance of having a statewide consumer-run organization in order to sustain disaster relief after the acute aspect has passed. Applications for funding, coordination with other agencies, and cooperation among different parts of the state, all require the sustained involvement of peers. The experiences in New York City following 9/11 illustrated how a strong, local, consumer-run organization can be a useful adjunct to professional services in time of disaster. As such, there is a pressing need to ensure that consumers are involved in all levels of disaster planning. In keeping with President George W. Bush's New Freedom Commission Report, which calls for a consumer driven system that includes peer support, in the future federal and state agencies involved in disaster relief must ensure that there is significant consumer participation in the planning, training for, and delivery of disaster relief services.

Specific Recommendations:

- 1. Proposal for a National Consumer Recovery from Disaster Network with representatives from each state. SAMHSA could fund such a network, with coordination by the three consumer-run TA Centers. This network could build on the work of CORK. It could help ongoing training of consumers in each state in disaster readiness. This training could include Peer Crisis Support as well as personal disaster planning. This network could assist local groups to cope more effectively at times of crisis. It also could help in coordination of peer support with SAMHSA, FEMA, and State Departments of Mental Health.
- 2. Training must include disaster response training; contact options or "calling trees" when telephone lines are unavailable; warmlines; trauma aftercare; outreach programs; an emergency medication program; and finally, long term approach to mental health services.
- 3. Need for proactive preparation in each state through development of a strong consumer-run, statewide organization capable of drawing on the national consumer network to establish an accessible site for centralizing resource materials, and coordinating a peer trauma training program.

Additional recommendations which have been developed by the After the Crisis Initiative's Peer Support Model Development Workgroup:

- 4. Creation of Consumer Technical Assistance Centers provide funding for Centers to support development bringing these TA Centers into the discussion with The National GAINS Center, The Center on Women, Violence and Trauma (CWVT), and The Center for Mental Health Service (CMHS), as well as survivor organizations
- 5. Overarching support and TA from CMHS and Centers to provide guidance and support (mentorship) around what strategies to use. Develop National disaster plan based on these principles: National Disaster Recovery Network based upon LACORK model, National VOAC, National Case Management Consortium (VOA, SA, Catholic Charities, others) reach out to existing consortiums/organizations that are already preparing/providing disaster response to incorporate these key principles in their response efforts
- 6. Involve Homeland Security in a conversation at the federal level, continuing discussion at state level (state disaster plans are under auspices of federal and/or state Departments of Homeland Security)
- 7. Proceed with a public education campaign focused on connecting with others "you've been through a lot, it's okay to talk about it" normal reactions to abnormal events everybody has a story to tell
- 8. Develop on-line database to serve as repository for information (programmatic or otherwise) and resources and continue the discussion related → repository of programs (promising, EBPs)/peer support models → providing information and linkages → develop program descriptions of promising programs (NYC, LA, OK, AL, etc.) as exemplars of what models exist

- 9. Go beyond a database to continue connections and foster relationships by facilitating collaboration and working together. Hold a series of meetings to complement the database activities stories need to be told
- 10. Build evaluation capacity into development efforts and seek to build evaluation data on existing programs Making efforts as of NATIONAL SIGNIFICANCE, have a Coordinating Center to manage this process, collect and analyze data, document promising programs/practices and EBPs → greatly support/influence Congress/Policymakers
- 11. Rethink how agencies relate to the field it's not bringing people to the table, it's going to their tables → working locally/keeping locus of control at local level → integration happens at the local and individual level, which is at the heart of peer support → use community organizing as a tool to stimulate change

References

- Ahern, L. & Fisher, D. (2001). Recovery at your own PACE. *Journal of Psychosocial Nursing*, 39, 22-32.
- Allen, J. (2005). What self-help/peer supports groups can do in time of disasters and emergencies. (Available from: John Allen, Office of Mental Health, 44 Holland Avenue, 8th Floor, Albany, NY 12229).
- Bandura, A. (1977). Social learning theory. Englewood Cliffs, NJ: Prentice-Hall.
- Campbell, J. (2005). *The historical and philosophical development of peer support programs*. In S. Clay (Ed.), On Our Own, Together: Peer Programs For People With Mental Illness (pp. 17-66). Nashville, TN: Vanderbilt Press.
- CORK team. (2005). Beyond relief to recovery, a manual used in training the peers in Louisiana to be peer trainers. (www.power2u.org).
- Festinger, L. A. (1954). A theory of social comparison processes. *Human relations*, 7, 117-140.
- Felton, C. J., Stastny, P., Shern, D. L., Blanch, A., Donahue, S., Knight, E., et al. (1995). Consumers as peer specialists on intensive case management teams: Impact on client outcomes. *Psychiatric Services*, 46(10), 1037-1044.
- Fisher, D. (2006). Recovery from schizophrenia: From seclusion to empowerment. Medscape, *Clinical Update*, Available from: http://www.medscape.com/viewprogram/5097?src=hp12.infocus
- Hardiman, E., Carpenter, J., Jaffee, E., & Gourdine, D. (2005). *An evaluation of peer mental health disaster relief services in New York City*. Albany, NY: School of Social Welfare.
- Holter, M. C., Mowbray, C. T., Bellamy, C. D., MacFarlane, P., & Dukarski, J. (2004). Critical ingredients of consumer-run services: Results of a national survey. *Community Mental Health Journal*, 40(1), 47-63.
- Klein, A. R., Cnaan, R. A., & Whitecraft, J. (1998). Significance of peer social support with dually diagnosed clients: Findings from a pilot study. *Research on Social Work Practice*, *9*, 529-551.
- Mead, S. (2005). *Peer support: An alternative approach*. Available from: http://www.mentalhealthpeers.com/pdfs/orderform.pdf.
- Mead, S., Hilton, D., & Curtis, L. (2001). Peer support: A theoretical perspective. *Psychiatric Rehabilitation Journal*, 25(2), 134-141.

- Moynihan, P. J., Levine, J. M., & Rodriguez, O. (2005). The experiences of Project Liberty Crisis counselors in the Bronx. *Community Mental Health Journal*, 41(6), 665-673.
- New Freedom Commission on Mental Health. (2003). *Achieving the promise: Transforming mental health care in America. Final report.* (DHHS Publication No. SMA-03-3832). Rockville, MD: Government Printing Office.
- Salzer, M. (2004). *Best practice guidelines for consumer-delivered services*. Evanston, IL: Center for Psychiatric Rehabilitation.
- Salzer, M. & Mental Health Association of Southeastern Pennsylvania Best Practices Team (2002). Consumer-delivered services as a best practices in mental health care and the development of practices guideline. *Psychiatric Rehabilitation Skills*, 6, 355-382.
- Substance Abuse and Mental Health Services Administration. (2005). Peer support: Disaster preparation for people with psychiatric disabilities. Available from http://www.connectlive.com/events/samhsa/.
- Solomon, P. (2004). Peer support/consumer provided services, underlying processes, benefit, and critical ingredients. Draft.
- Solomon, P., & Draine, J. (2001). The state of knowledge of the effectiveness of consumer provided services. *Psychiatric Rehabilitation Journal*, 25(1), 20-27.
- Stern, D. (2004). The present moment. New York, NY: W.W. Norton & Company Inc.
- Zimmerman, M. A. (1990). Toward a theory of learned hopefulness: A structural model analysis of participation and empowerment. *Journal of Research in Personality*, 24, 71-86.